A good read

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Chapter 2 Tell me a story

Multi-sensory storytelling for persons with profound intellectual and multiple disabilities: an analysis of the development, content and application in practice.

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2.1 Introduction

We tell stories about what happens in everyday life or about events that have happened in the past or in our imagination. Stories can enable us to construct our role in the world. However, storytelling can also be used to socialize children, to teach them what is appropriate or important, or to equip and encourage them to become storytellers themselves (Cassell & Ryokai, 2001). Storytelling is a unique human experience (Park, 1998), and people with profound intellectual and multiple disabilities (PIMD), despite their disabilities, should also be enabled 'to participate in those experiences which are uniquely human' (Ware, 1994). But professional practice shows a different picture. Apparently, in persons with PIMD, their profound intellectual and motor disabilities, combined with sensory disabilities, can constitute a barrier to those who, at least in a professional situation, would act as natural storytellers. This is because telling a story is a primarily verbal and communicative activity in which comprehension of the storyline is an important element. This makes storytelling a seemingly illogical activity choice for persons with such profound disabilities.

Yet several authors state that access to literature must not depend on the ability to read, to speak or even to understand the spoken words (Grove, 1998; Park, 1998), because storytelling is not only about comprehension (understanding the content of a story) but also about apprehension – the enjoyable experience of having someone sitting next to you, perhaps making eye contact, while you listen to the sound of their voice (Grove, 1998). Both ideas, that of 'inclusive literacy' and the notion that 'apprehension comes before comprehension' (Grove, 1998),

have in recent years led to the exploration of the potential of storytelling to enhance the lives of people with PIMD. Storytelling has been developed within a framework of sensory-based and socially interactive approaches, starting with Fullers 'bag books' (Fuller, 1990) and further developed by PAMIS – a third sector organization – e.g. Watson and colleagues (Watson, Lambe, & Hogg, 2002) and Grove (Grove, 2005; Grove, 2009). These 'multisensory stories' are tailor-made, personalized stories that stimulate the senses rather than 'just' using words. The content and form of the story, and the way the story is read, is adapted to the abilities, needs and desires of the individual with disabilities. The story reflects aspects of the person's life and personality, and relates to an event or situation that is important for him or her. Each page is illustrated by an object, and this object is meant to attract the person's attention and invite him or her to explore. For example, telling a story about the car that comes to pick up that person for an outing can be illustrated by using the sound of a claxon. In this way, the storytelling activity can generate pleasure and engagement, as well as an opportunity for a qualitative one-to-one interaction between the person with PIMD and his or her direct support professional (DSP).

For the development of an multi-sensory storytelling (MSST) book, PAMIS has formulated specific guidelines (see Table 1).

An MSST book, like a regular book, has a title, a beginning and a clear end. The story is personalized to facilitate the recognition of the story by the person with PIMD. Furthermore, the book consists of only a few pages (a maximum of eight) and every page includes one or two

Table 1

PAMIS guidelines used to assess the MSST books

	Constructing a multisensory storytelling book	Reading a multisensory storytelling book
Book in general	- a title is present - the story has a clear end - sentences are written on a story script	- DSP takes time to read the book (4-6 minutes)
Sentences	- max. of two sentences per page - sentences are directly related to the stimuli	- no additional text is used in addition to the original story script
Pages	- one white board per one or two sentences - white boards are present - max. of eight pages	- white boards are used
Stimuli	- stimuli are attached to the white boards - max. of one stimulus per page, which may address multiple senses	- stimuli are actively offered to the person

sentences because of the short attention span of the person with PIMD. Each page is supported by a stimulus that draws attention and facilitates the exploration of the person. The stimuli are offered on neutral backgrounds (blank pages) to increase contrast and therefore visibility, the neutral background also helps the person with PIMD focus faster, which results in a reduced reaction time. After showing a stimulus on a neutral backgrounds, the stimulus is offered to the listener in an active way to maximally engage the person with PIMD (Lambe & Hogg, 2011).

With regard to the application of the MSST book, it should be read in the same way each time in terms of word use and setting. By repeating the story, the listener may learn to recognize the story by association (Rock, 1957) and enables the person with PIMD to get to know their personal story and the stimuli used in that story. This sense of having control over the environment, the feeling of 'knowing that something is coming', and the opportunity to anticipate is expected to positively influence the person's sense of involvement and wellbeing (Lambe & Hogg, 2011; Petry, Maes, & Vlaskamp, 2005).

But just following these guidelines does not make a good MSST book, which is formed around the characteristics, personality, experiences, preferences and abilities of a person with PIMD. In other words, in MSST, the content, form and presentation of the story need to be adapted to the person with PIMD to facilitate the 'apprehension' of the story (Fuller, 1990; Grove, 1998). Therefore, knowledge about the abilities and sensory as well as contextual preferences of a person with PIMD is essential (Vlaskamp et al., 2007). Once a topic is decided upon and the story itself is written, suitable stimuli have to be selected. For example, when making a book about dinnertime, it is important to know whether the person with PIMD associates a spoon with eating before you select this stimulus. It is also important to know how the stimuli should be presented. Should the spoon be presented to the individual's left or right? Can the individual actually see the spoon or does he or she need to touch it? Also, information must be collected about the reading context, for example, can the story be read in a living room where there is ambient sound present?

MSST is used frequently in the United Kingdom and was recently introduced in the Netherlands and Belgium (Flanders) where it is implemented in a growing number of facilities for persons with intellectual disabilities. However, despite the frequent use of MSST, little research is being conducted into the structure, content and effectiveness of the intervention (Lambe & Hogg, 2011). This is only one example of practitioners using a method for which researchers have shown limited interest in providing an empirical basis. To provide such a basis, the implementation of the method needs to be followed by research (Vlaskamp & Nakken, 2008). A first step in this process is to analyse to what extent the stories developed by DSPs follow the PAMIS guidelines. Furthermore, the topics that are addressed by the DSP to clarify the content of the stories and which stimuli are used should also be known. Finally, it is important to know how specific information regarding the person with PIMD and his or her age affects the application of the story by the DSP.

So, in this study three topics will be addressed: 1. the development of the MSST book in terms of applying the PAMIS guidelines, 2. the content of the developed stories and stimuli used, and 3. the application of the MSST book and how the age of the person with PIMD and information about the person with PIMD from the DSP affects the choice and content of the stories. Therefore, the following questions have been formulated:

(1) Are MSST books constructed and read in accordance with the PAMIS guidelines?
(2) What is the content of the stories and which stimuli are used?

(3) Is there a difference between children and adults in content and type of stimuli used in the story?
(4) Is the DSP's knowledge about the functional and sensory abilities and the sensory preferences of the person with PIMD related to the choice of stimuli?

2.2 Materials and Methods

2.2.1 Participants

Forty-eight DSPs applied voluntarily to implement MSST within their care facility and to monitor this implementation by research. Twelve responded to an appeal placed on a website; the remainder (n = 36) were recruited internally by healthcare psychologists who were notified of the planned research project. The study took place in 25 residential facilities in the Netherlands and Belgium spread across 29 different group homes and activity centres (18 in the Netherlands, 11 in Belgium). The maximum number of participating DSPs per location was three. The DSPs ranged in age from 20 to 61 years (mean age: 38.4). Their working experience with persons with PIMD ranged from 2 months to 31 years (mean: 10.6, SD 7.8). Each DSP formed a pair with a person with PIMD. A necessary precondition for the pairing was that the DSP had to be acquainted with the person with PIMD. The working experience of the DSPs with these particular persons ranged from 2 months to 15 years (mean: 3.6 years, S.D 3.3 years). All selected persons had PIMD, as defined by Nakken and Vlaskamp (2007), meaning that they were diagnosed with a developmental age of less than 24 months

and with profound or severe motor disabilities, as well as a high prevalence of sensory impairments and general health problems. Of the selected persons with PIMD, 23 were female and 26 male. The group comprised 26 children (<18 years; mean age 10.3 years, range: 4-15, SD: 3.9) and 23 adults (≥18 years, mean age: 38.5, range: 19-70, SD: 13.9). Each of the 48 DSPs developed an MSST book for that particular participant. One DSP made a story for two different persons. We can differentiate two groups within the development of the MSST. The first group, consisting of 28 DSPs and 29 persons with PIMD, used an instrument (the 'Inventory for tuning activities and situations to the abilities and preferences of persons with profound intellectual and multiple disabilities', IPP) before constructing the book. The IPP (Tadema, Hiemstra, Wiersma, & Vlaskamp, 2005) can provide additional information for the development of an MSST book. The second group (consisting of 20 DSPs) did not use the IPP.

2.2.2 Instruments

Information concerning the demographic characteristics of the DSPs (age, gender and working experience) was collected by means of a short questionnaire.

Information on DSP knowledge about the sensory and contextual preferences of the persons with PIMD was determined using the IPP (Tadema et al., 2005). This questionnaire takes the form of a flow chart and is divided into nine categories. Five of these relate to an individual's functional abilities (visual, auditory, tactile, olfactory and motor skills), while the other four relate to their sensory and contextual preferences (preferred sensory channel, preferred 'where', 'when' and 'how' of

activities offered). In total, the nine categories of the IPP consists of 35 questions. Each question covers an aspect relating to a specific category. For example, the following questions are asked in the 'auditory' category: 'Should pitch be taken into account?', 'Should volume be taken into account?' and 'Should the number of stimuli be taken into account?' Each question can be answered by 'yes' or 'no'. A third option is to leave the question unanswered. This indicates that there is no knowledge available on this particular subject, which means that the DSPs are indecisive about the abilities and preferences of the person with PIMD (Van der Putten, Vlaskamp, & Schuivens, 2010; Vlaskamp et al., 2007). The aim of the IPP is to organize the present knowledge about the preferences and abilities of the person with PIMD in a convenient way that enables the DSP to use this knowledge while creating an activity (Vlaskamp et al., 2007).

2.2.3 Procedure

To develop the MSST intervention, all DSPs from the first group filled in the IPP for each of the participants (one DSP filled it in for two participants). The second group of DSPs (n = 20) did not use the IPP but used existing knowledge about the person with PIMD, recorded in personal planning files. Next, all DSPs (from both groups) underwent a workshop training which consists of theoretical information about the underlying assumptions and guidelines of MSST. Then the DSPs had to construct an MSST book: write the text and 'fill the box' (i.e. collect the right stimuli, pin them on white boards, etc.).

Once the MSST book was made, the DSP read it twice a week with the person with PIMD for a period of ten weeks (the first group) and five

weeks (the second group). This difference in the duration of the study is based on practical reasons. The first, fifth and tenth reading sessions for both groups and the twentieth reading session (the first group only) were recorded on video.

2.3 Results

2.3.1 Are MSST books constructed and read in accordance with the PAMIS guidelines?

First, we checked that the MSST books had been constructed in accordance with the PAMIS guidelines (PAMIS, 2010) formulated in table 1. All 49 MSST books were used in the analysis. An analysis was carried out for each individual guideline to assess whether or not the MSST book met this particular guideline (yes or no). To analyse the reliability of this procedure, 43% (n = 21) of the books were randomly selected and assessed by two independent researchers. Inter-rater reliability was good (90% agreement).

Table 2 shows that the majority (84%, n = 41) of the MSST books satisfied all the PAMIS guidelines.

There were eight exceptions. Three books (6.4%) had too many sentences and five books (10.6%) used two or more different stimuli per page (e.g. singing a song and giving a hug).

Table 2

PAMIS guidelines for constructing a multisensory storytelling book

	Constructing a multisensory storytelling book	Number of books	Percentage of books (n=49)
Book in general	a title is present	49	100
	the story has a clear end	49	100
Sentences	sentences are written on a story script	49	100
	max. of two sentences per page	47	96
	sentences are directly related to the stimuli	49	100
Pages	one white board per one or two sentences	47	96
	white boards are present	49	100
	max. of eight pages	48	100
Stimuli	stimuli are attached to the white boards	49	100
	max. of one stimulus per page, which may address multiple senses	43	88
Total	Number of books conforming to all guidelines	41	84

To find out if the books were read according to the PAMIS guidelines, the recordings of 157 reading sessions from both groups were used. A total of 11 sessions (7%) were missing because the person with PIMD was ill or the pairs had withdrawn for other reasons. Each first, fifth, tenth and – for the first group – twentieth reading session was filmed to monitor whether the books were read according to the guidelines. More specifically, an analysis was made of the story's

duration (in seconds), the number of stimuli offered on the neutral backgrounds, the number of stimuli the person with PIMD had physical access to and whether or not the DSP added verbal text to the original story (see Table 1). To establish changes in duration throughout the reading sessions, the first session for each pair was used as a baseline. The discrepancies in seconds between the first and, respectively, the fifth, tenth and twentieth reading sessions were calculated. Differences between the first, fifth, tenth and twentieth reading sessions in terms of duration, the active presentation of stimuli and the use of white boards were analysed with a paired sample t-test. Where there is a likelihood of a type one error, a repeated measure analysis is usually used. However, because of the 11 missing sessions and the differences in research design between the two groups (three versus four recordings), we opted for a paired t-test as a repeated measure analysis would omit a substantial number of cases.

Results show that the mean duration of the reading sessions was six and a half minutes (SD = 4 min. and 12 sec.), with a range between 83 and 1421 seconds. In total, 40 reading sessions (25.5%) met the four-to-six-minute guideline according to PAMIS. The other sessions were shorter (n = 74; 47.1%) or longer (n = 43, 27.4%). On average, the first session was the shortest. The fifth reading session was the longest, lasting on average fourteen seconds longer than the first. Both the tenth and the twentieth sessions took seven seconds less than the fifth. These differences between the four sessions are not statistically significant (see Table 3).

Table 3

Differences in time spent reading, the use of white boards and the active presentation of stimuli between the first, fifth, tenth and twentieth reading sessions using a paired sample t-test

			Session number					
			Fifth		Tenth		Twentieth	
			t	df	t	df	t	df
Session number	First	Time spent reading	-.59	40	-.35	41	-.52	21
		White boards	-.79	40	.33	41	-.12	21
		Active presentation	.49	40	.40	41	.89	21
	Fifth	Time spent reading	-	-	-.05	37	-1.57	17
		White boards	-	-	1.55	37	1.53	17
		Active presentation	-	-	-.22	37	.70	17
	Tenth	Time spent reading	-	-	-	-	-.07	18
		White boards	-	-	-	-	-.83	18
		Active presentation	-	-	-	-	.48	18

* $p < .05$

** $p < .01$

The PAMIS guidelines recommend the use of neutral backgrounds. We counted the number of neutral backgrounds used in all of the 157 recordings. In 51 of them (32.5%), neutral backgrounds were used at all. In 31 reading sessions five or more stimuli were presented on a white board; in 80 recordings two or fewer neutral backgrounds were used. There were no significant differences between the four time measurements in the use of neutral backgrounds (see Table 3).

Regarding the way stimuli were offered, results show that not all the stimuli in the MSST books were presented in a way that allowed the person with PIMD to actively engage with them. On average 4.2 stimuli

per reading session (SD = 2.11) were presented actively, with a minimum of zero stimuli per session and a maximum of nine. In forty (25%) reading sessions, zero to two stimuli were offered actively, meaning the person could touch or manipulate the objects. In almost a third (n = 46, 29.3%) of the sessions, five or more stimuli were offered actively. There were no significant differences between the four time measurements and the number of stimuli presented actively (see Table 3).

Furthermore, we analysed to what extent text was added spontaneously to the original text of the story. Results show that in 73.2% of the recorded reading sessions, text was spontaneously added. This ranged from comments on the behaviour of the person with PIMD ('You are doing well, do you like it?', 'Oops, you're sneezing! Are you all right?') to a supplement to the story (the original text 'We are going to put on the doll's clothes' was supplemented by 'Yes we are! First the shoes, then the shirt, then the trousers, that's really good... you see? Now the doll is fully clothed!'). Of the 47 DSPs, 11 (23.4%) never used the original text of the story and only three (6.4%) always adhered to the story.

When all the criteria for reading the MSST books are taken into account, only five (3.2%) of the 157 reading sessions involved the use of all predetermined criteria (the active presentation of stimuli and the use of neutral backgrounds and additional text). If we also look at the duration of the story (between four and six minutes), only two (1.3%) reading sessions met all the guidelines.

2.3.2 What is the content of the stories and which stimuli are used?

For the analysis of the content, 46 MSST books were used, three books were omitted because they did not meet the PAMIS guidelines in terms of the number of sentences. Table 4 shows an overview of the content of the books with six categories identified. Activities and excursions differ in that the former take place within the facility and the latter take place outside. Activities and excursions are divided into imaginary (fantasy) events and daily life events (such as having a bath or going for a walk). The 'party' category (e.g. birthday party) is a separate category because of its non-functional nature – in contrast to daily life events – but parties cannot be characterized as imaginary activities or excursions. Books about 'preparation' may include, for example, stories about going home in the weekend. More than half of the books (52.2%) were about 'real life' excursions such as taking a walk or going to see the horses, followed by 17% about 'preparation'. Fantasy topics were less represented (n = 4; 8.4%).

With regard to the senses the stimuli appealed to, stories that failed to comply with the PAMIS guidelines on the maximum number of sentences and stimuli were omitted (n = 8). A total of 41 books were used in this analysis. To analyse the stimuli used, books (n = 41) were categorized on the basis of the description of how the stimulus was presented (e.g. 'let her put her hands in the bowl to feel the water') and of the senses they appealed to. Six senses – auditory, visual, tactile, olfactory, taste and balance/propriocepsis (e.g. the physical sensation of moving the wheelchair in a circle) – were identified in total. In each

Table 4

Book content according to the age group of the person with PIMD, whether or not the IPP was filled in and regardless of DSP indecisiveness

	Content (n=46)						Age				If IPP is filled in		
			First group		Second group		child		adult		Books (n)	Mean indecisive questions	SD
	N	%	N	%	N	%	N	%	N	%			
Preparation	8	17.4	3	10.3	5	29.4	5	19.2	4	17.4	3	9.7	5.03
Excursion (daily life)	24	52.2	15	51.7	9	52.9	13	50.0	12	52.2	15	8.0	6.70
Excursion (fantasy)	2	4.3	2	6.9	0	0	1	3.8	1	4.2	2	7.0	1.41
Activity (daily life)	7	15.2	5	17.2	2	11.8	5	19.2	2	8.3	5	9.6	4.61
Activity (fantasy)	2	4.3	2	6.9	0	0	1	3.8	1	4.2	2	1.0	0
Party	3	6.5	2	6.9	1	5.9	1	3.8	3	13.0	2	15.0	7.07
Total	46	100	29	100	17	100	26	100	23	100	29	8.4	6.07

story, the number of stimuli that appeared per sense was calculated. Combinations of senses were also included; these were counted separately (for the different categories, see Table 3). The most frequently used stimuli were auditory (listening to a song) and tactile (feeling a specific structure or touching water) (see Table 5). Tactile stimuli were used the most. On average, these stimuli appeared 2.5 times per book. In each book, an average of 1.5 stimuli targeted multiple senses, with an

auditory/tactile combination the most popular (squeezing a horn and listening to the sound).

Table 5

Senses activated by the stimuli, according to presence of indecisiveness and age group

	Total							Age group				
	(n=41)		First group		Second group		t-value	child		adult		t-value
	mean	SD	mean	SD	mean	SD	(df = 47)	mean	SD	mean	SD	(df = 47)
Auditory	1.7	1.07	1.8	1.12	1.7	0.99	-0.62	1.9	1.58	1.8	1.03	0.15
Visual	0.8	0.87	0.8	0.97	0.8	0.62	0.28	0.7	1.05	0.9	0.85	-0.80
Tactile	2.5	1.31	2.3	1.37	2.8	1.14	-0.01	2.3	1.49	2.4	1.12	-0.44
Olfactory	0.2	0.38	0.2	0.38	0.2	0.39	0.70	0.2	0.37	0.1	0.34	0.23
Taste	0.02	0.16	0.03	0.19	0	0	0.83	0	0	0.04	0.21	-1.07
Balance and/or propriocepsis	0.1	0.26	0.1	0.31	0	0	1.49	0.04	0.2	0.1	0.29	-0.70
Auditory & visual	0.3	0.63	0.2	0.49	0.4	0.9	-1.29	0.5	0.81	0.1	0.29	2.31*
Auditory & tactile	0.5	1.03	0.6	1.06	0.5	1.0	-0.16	0.6	1.24	0.5	0.73	0.32
Visual & tactile	0.4	0.71	0.5	0.69	0.3	0.78	0.40	0.6	0.76	0.3	0.64	1.36
Olfactory & tactile	0.2	0.51	0.2	0.47	0.3	0.62	-0.19	0.1	0.33	0.3	0.62	-1.05
Visual, tactile & olfactory	0.1	0.22	0.1	0.26	0	0	1.19	0.04	0.20	0.04	0.21	-0.09

* $p < .05$

** $p < .01$

2.3.3 Is there a difference between children and adults in content and type of stimuli used in the story?

For the analysis between children and adults with respect to content of the story and use of stimuli, all MSST books (n = 49) were used. The distribution of observations between age-group and content was analysed by means of a chi-square test, which looked if the distribution of adults and children across the different content types deviated from the expected count. The differences in age group regarding the stimuli used was analysed by categorizing the stimuli in terms of the senses to which they appealed and counting per story how many stimuli of the specific sense were used. After this, the number of stimuli in the different categories (e.g. auditory and visual/tactile) were set across from the two age groups to compare differences in stimuli used. An independent sample t-test was used to see if there was a significant difference between the two age groups.

Compared to adults, children were read more books focusing on an 'activity in daily life' (see Table 4), although this difference in the distribution of the groups is not statistically significant ($\chi^2 = 2.26$, df = 5, NS).

If we compare the stimuli used within the different age groups, we observe one statistically significant difference in the distribution of the groups: the combination of auditory and visual stimuli is used more often for children than for adults ($t = 2.31$, df = 47, $p < .05$) (see Table 5).

2.3.4 Is the DSP's knowledge about the functional and sensory abilities and the sensory preferences of the person with PIMD related to the choice of stimuli?

As stated before, in group one the IPP was used in constructing an MSST book. We analysed whether the use of the IPP influenced the content and choice of stimuli. The content was analysed by means of a chi-square test, which looked at the distribution of the first and second groups across the different content types. The relationship between the stimuli and the use of the IPP was analysed by categorizing the stimuli in terms of the senses they appealed to and comparing the mean number of stimuli in the different categories (e.g. auditory, visual/tactile) across the first and second groups with an independent sample t-test. Then we further specified the results of the IPP and the influence this had on the construction of an MSST book by analysing the amount of information available about each person and the amount of information missing for the DSP (e.g. if the DSP does not know whether an object is best presented to the left or right of the person's visual field, the DSP cannot answer the question in the IPP). We looked at the number of questions in the IPP with no answers. Using an independent sample t-test, we looked for differences between the age groups and the number of unanswered questions in the IPP. A one-way ANOVA was used to calculate the mean number of unanswered IPP questions across different types of content. A Pearson's correlation coefficient was used to analyse the relationship between the number of unanswered questions about sensory abilities and preferences, and the number of stimuli for each sense.

There is no significant difference in distribution of the groups between 'filling in the IPP' (yes or no) and book content (χ^2 = .48, df =5, NS) (see Table 4), nor a relationship or difference between the two DSP groups and stimulus use (see Table 5).

The DSPs were able to answer the majority of the IPP questions (76%). In total, 24% of the questions (mean 8.4 questions per person, SD = 6.1, range = 0-20), were not answered which means that the DSP did not have this knowledge. The total number of unanswered questions was significantly higher for adults than for children (t = -2.69, df = 27, p < .05, R^2 = .29) (see Table 6).

Table 6

Items answered indecisively, according to age group

(n=29)	Number of items	Total mean / SD	Child mean / SD	Adult mean / SD	t-value df = 27
Visual	6	1.4 / 1.45	1.3 / 1.62	1.5 / 1.29	-0.43
Auditory	4	0.7 / 1.03	0.3 / 0.62	1.1 / 1.23	-2.26*
Tactile	4	1.1 / 1.18	1.0 / 1.25	1.2 / 1.12	-0.48
Olfactory	4	2.4 / 1.78	1.6 / 1.7	3.3 / 1.49	-2.85**
Stimuli preferences	4	1.1 / 1.07	0.5 / 0.83	1.6 / 1.01	-3.24**
Contextual preferences	13	1.7 / 1.79	1.0 / 1.31	2.4 / 1.90	-2.30*
Total	35	8.4 / 6.07	5.7 / 5.17	11.2 / 5.81	-2.69*

* p < .05

** p < .01

In table 6 is the average number of unanswered questions for adults and children is worked out. In addition, whether or not a significant

difference exists between the two age groups is indicated. Only the number of unanswered questions in the visual ($t = -.43$, $df = 27$, NS) and tactile ($t = -.48$, $df = 27$, NS) domains does not differ significantly between these age groups.

Further detailed analyses (see Table 4) show that DSPs who were more indecisive about the person with PIMD were more inclined to write a book about a party than about imaginary activities (respectively 15 and 1 unanswered questions). However, the difference between the number of unanswered questions per content category is not significant ($F = 1.44$, $df = 5$, NS).

When combining indecisiveness about the preferences and abilities for all senses (visual, auditory, tactile and olfactory), we see a statistically significant positive relationship between indecisiveness and the use of visual ($r = .44$, $p < .05$) and olfactory ($r = .41$, $p < .05$) stimuli. Visual stimuli are mainly applied if the DSP cannot answer the questions about the person's visual ($r = .46$, $p < .05$) or auditory ($r = .49$, $p < .01$) abilities and preferences. If there are more unanswered questions regarding the tactile preferences and possibilities, a DSP is likely to include more stimuli targeting smell ($r = .51$, $p < .01$).

2.4 Conclusion and discussion

The focus of this study was threefold. First, we analysed the extent to which MSST books are constructed and used according to PAMIS guidelines. Second, we analysed the content, including the stimuli used and how this relates to the age of the person with PIMD and the DSPs

knowledge regarding the functional and sensory abilities and the sensory preferences of the person with PIMD.

Results show that the majority (84%) of the MSST books were developed in line with the MSST guidelines described by PAMIS (Lambe & Hogg, 2011). Deviations from the guidelines included the use of too many sentences and too many stimuli per page.

When the books were read or applied in practice, many DSP did not follow all the PAMIS guidelines. During most reading sessions (47%= 74) the book was read too fast, the prescribed use of white boards was frequently not adhered to, and the stimuli (38%) could not be explored actively. Moreover, in the majority (73.2%) of sessions, text was added spontaneously to the original text.

As for content, the vast majority of the books (67.4%) were about a 'real life' activity or excursion (e.g. an outing). Fewer than 10% of the books were about an imaginary activity or excursion (e.g. building a home) and 20% were about preparation (e.g. for medical treatment). There is no significant difference in story content between children and adults.

DSPs mainly used tactile and auditory stimuli in addition to the vocal text. In six (12.8%) books, more than one stimulus per page was used and nearly 20% of stimuli targeted more than one sense, such as touching an object and listening to a sound. Other combinations included feeling perfume sprayed on the skin and smelling the fragrance, or looking at and touching a balloon. When the application was related to the age of the person with PIMD, results show that the choice of

stimuli differs significantly per age group, with children being offered more stimuli targeting a combination of visual and auditory senses than adults.

With regard to the relationship to the use of the IPP (knowledge about the ability and preferences of the person with PIMD), DSPs chose more visual and olfactory stimuli when they still had questions about these topics (were indecisive about the sensory preferences and abilities of the person with PIMD). Visual stimuli were selected more often when there was less information about auditory and visual preferences and abilities. Olfactory stimuli were more frequent when there was more indecisiveness about the person's tactile sense, nor is there a relationship between the content of the MSST books and whether or not the IPP was filled in.

Before we interpret these results, some methodological reflections would be helpful. In this study, we made a distinction between two groups of DSPs who attended two different workshops. In addition to whether or not the IPP was used, there were further slight differences between the two workshops. The first group of DSPs, which included using the IPP, received less feedback from the researchers while writing the story and the PAMIS guidelines were made more explicit during the workshop. This may explain why the second group used additional words more often (they used additional text in 93% of the reading sessions) than their counterparts in group one. This may also have influenced the duration of the reading session. In addition, the workshops were given in different countries and by different instructors. These factors could interfere with the effects found and influence the

generalization of the effects. The duration of the research also differed per country (ten versus five weeks). Because of the nature of this research (a monitored intervention) and the choice of statistical analyses, there is no reason to assume that this particular difference has influenced the results.

Results show that most DSPs (84%) were capable of making a book according to the guidelines after one short workshop, but they experienced greater difficulty following the guidelines when reading the book. On the other hand, the results show that most DSPs read the books too quickly and frequently added words or sentences to the story.

It is clear from the results that the content of the books in our sample mostly relates to the person's real life. There seems to be a strong focus on 'comprehension' by persons with PIMD. The lack of difference in content between children and adults is remarkable. This suggests that the content of MSST books is less age-appropriate, and thus in line with other data showing that offering 'age-appropriate' activities to persons with PIMD is a challenge (Forster, 2010; Matson, Bamburg, & Smalls, 2004; Vlaskamp et al., 2007). We expected to see a variety of stimulated senses in MSST books, but 70% of the stimuli targeted the auditory and/or tactile senses. In particular, the decision to support the MSST book with a relatively high number of auditory stimuli seems less obvious, since hearing is already an important element of MSST because of the vocal text an MSST book contains. One might therefore expect DSPs to use few auditory stimuli in their books.

The use of an instrument (the IPP) facilitates DSP awareness of the need to know about the person's abilities and preferences. Results show a

significant relationship between the use of visual and olfactory stimuli and the lack of this prior knowledge about sensory preferences and abilities. In this sense, the use of a visual stimulus can be seen as a 'safe choice'. Surprisingly, they are also used more often when there is less information in the IPP concerning the visual sense. An olfactory stimulus seems more like an alternative choice for a tactile stimulus. Indecisiveness about one sense influences the frequency with which other senses are stimulated. We recommend using an instrument which identifies the preferences and abilities of persons with PIMD, especially when much is unknown about the sensory abilities and preferences. It may be helpful to use the IPP, collecting additional information if necessary, before constructing an MSST book.

MSST is a rather new but increasingly popular activity for persons with PIMD. It is not easy to implement a new method (like MSST), and our results show that even controlled implementation by researchers does not prevent serious departures from the guidelines. Even with the development of sound guidelines to optimize engagement of the person with PIMD, it is likely that time pressure when implementing a new method will mean that some parts of the method will be set aside, adapted or even eliminated (Vlaskamp & Van der Putten, 2009). When implementing a new intervention, commitment to a long-term process is needed. Even a period of 20 reading sessions is scarcely enough time to predict the further use of the method. In particular when deviations from guidelines are already present at the outset, one may wonder how this will affect the effectiveness of the method. Apparently a one-day training period is enough to create MSST books according to the guidelines, but not sufficient to guard the guidelines in the long term. Knowledge

acquired during the workshop may fade in time; therefore, there is a need for alternative instruction and the frequent monitoring of the reading of the MSST book. Consequently, future studies should focus on the impact of these departures from the rules on the effectiveness for a particular person with PIMD and should take account of long-term use of the method.